

Special Addition

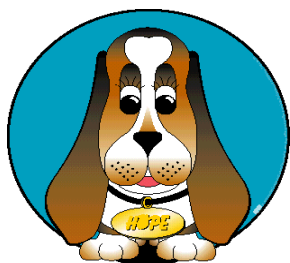


children with special health care needs

fall/winter 2003

A NEWSLETTER FOR MISSOURI FAMILIES

A publication of the Missouri Department of Health and Senior Services, Bureau of Special Health Care Needs



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Federal Viewpoint

Making the transition from youth to adult medical care

by Merle McPherson, MD, Director, and Gloria Weissman, Deputy Director, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration

The President's New Freedom Initiative calls for removing barriers that prevent people with disabilities from living in their communities. In the New Freedom Initiative report, *Delivering on the Promise* (dated March 25, 2002), the Health Resources and Services Administration (HRSA), is acknowledged as the federal agency with program responsibility for



addressing the barriers to children and youth with special health care needs.

HRSA is charged with developing a plan aimed at eliminating those barriers. The report identifies the following target areas:

- comprehensive, family-centered

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Local Viewpoint

Dunn named state health director

On January 3, 2003, Richard C. "Dick" Dunn, 66, of Springfield, was named the new director of the Missouri Department of Health and Senior Services. He

previously served as the director of the Division of Aging until it was transferred from the Department of Social Services to the Department of Health in August 2001. At that time, Dunn became deputy director for senior services and regulation in the newly named Department of Health and Senior Services.

Governor Bob Holden stated that he chose Dunn as health director because he has a "diverse and extensive background in the health field." Dunn also has served on the board of directors of

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care;

- affordable insurance;
- early and continuous screening for special health care needs;
- transition services to adulthood.

The report also notes the following issues for families of children with special health care needs:

- need for family satisfaction, and
- complexity and organization of services resulting from fragmentation and multiple funding streams.

As states look at the health and welfare of its citizens and build community systems of care, youth with special health care needs should be considered carefully. The fact that more children with special health care needs are living to adulthood is wonderful and remarkable. Improved medical science, technology, and outstanding care may allow many to progress with their adult lives barely impacted. For others, however, adulthood may pre-sent chal-

lenges to attaining the milestones that most take for granted—education, employment, and independence.

Medical insurance

According to the Social Security Administration, there are nearly one million children under age 18 receiving Supplemental Security Income (SSI) payments based on disability. Another 500,000 adult recipients first became eligible as children.

Many more enter the SSI system as “adults” at age 18, when parents’ income and resources are no longer considered, even though their medical condition would have qualified them at an earlier age.

The actuarial projections are that a recipient who first starts receiving SSI as a child will collect payments for almost 30 years. This represents a significant dependence on federal and state funds. Even those who are able to graduate from high school and college are often unable to make the transition to employment and leave the SSI rolls. While there are probably a number of reasons for this, access to and utilization of health care seem to figure prominently.

The older the children are, the less likely it is they will have health insurance. For those receiving SSI and Medicaid, many lose that coverage at adulthood. For those who continue, however, once they age out of the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program, covered items and services drop significantly.

On the private insurance side, coverage under the plan of a parent usually has an age limit. While the age limit may or



Many youth and parents express strong ties to their pediatricians.

may not be extended if the youth has special health care needs, often the plan is either too expensive or inadequate to cover all of the youth’s needs.

If a youth is working, part-time and entry-level service jobs do not typically provide health insurance coverage. All of this adds up to the potential decreased access to and utilization of health care at the time the youth is making the transition to adulthood.

From child to adult medical care

The actual transition from pediatric to adult medical care can be a difficult process for youth with special health care needs. Many youth and parents express strong ties to devoted pediatricians who have provided treatment for long periods of time—if not entire lifetimes. Thoughts of changing providers can be frightening, especially if the idea is unexpected. Furthermore, many pediatricians are reluctant to turn over care of a patient with special health care needs to another pro-

Special Addition is a free newsletter published twice a year for families of children with special health care needs. MedWrite News, Inc., Cincinnati, Ohio (513-791-8582), provided the newsletter design and layout of the national news.

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This newsletter is partially funded by the Maternal and Child Health Bureau (MCHB).



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the Childrens' Trust Fund. The group's work includes programs designed to prevent child abuse and cases of "shaken baby syndrome." He is past executive director of Boys and Girls Town, a reformatory school for troubled youths.

Due to the resignation of Dr. Maureen Dempsey, the department has been without a director since January 2002. Ron Cates, chief operating officer, has served as interim director since that time.

Medical home-a winning team!



As a parent or guardian of a person with a special health care need, you know how challenging it can be to find a good physician you can work with, and then to find all of the other services you want for your child. Services may be provided by a primary care physician, several medical specialists, therapists, durable medical equipment providers, teachers, case managers, and others. Families sometimes say that they feel like they are working with a whole squad of players, coming and going, and they sometimes don't know who represents which agency. It may be a very confusing situation.

The squad with many players needs to be organized into a team, and that is where the "medical home" comes in. A medical home is not a building or a place. Rather, it is a point of collaboration and organization, involving you, your health care providers, and your service coordinator. This team is called a "family-professional partnership". As the person who knows

your child the best, you are the team leader. Your primary care provider provides the medical expertise and coordinates the medical care that is provided by all of the specialists. Your service coordinator knows about medical conditions and their treatment and knows about resources to address them. He/She will work with you and your primary care provider to assess your needs and develop a service plan based on your own concerns and priorities.

Every person with a special health care need should have only one plan, which is shared by all of the team players. The plan should be for a specified period of time, usually one year, but it should be flexible enough to be changed as needs and resources change. In order to develop and implement the plan, the team should meet, face-to-face as often as required to develop a good working relationship with each other. It will be very helpful if you, as the team leader, will take the time to know the various players and what they can do for you and your child. To be most effective, your teammates must know you and your child. This requires open communication of your needs, concerns, problems, and solutions. Over time, the team will share trust and respect for each other. It's a lot of work, but well worth the effort.

When everyone understands the plan and can follow through on all of the major "plays", then you have a winning team. The successful team will work together as a whole. Every member will be able to understand what needs to be done, by whom, and when. You will be informed about resources to address your child's needs at any given time. At one time, you may be concerned about an up-coming surgery and recovery, and later on you may be more concerned about school-based programs for you or your child. The team players will change over time, depending on the needs that are identified. At other times, team players will change because of outside factors.

Families of many of the children on Bureau of Special Health Care Needs pro-

grams recently changed service coordinators because of an operational change in the Bureau. Some families had to transition from a service coordinator who had worked with them for years to a new service coordinator at the local health agency. This is a very difficult change for anyone to make, but you must make the effort to begin working closely and developing teamwork with your new service coordinator. Your new service coordinator also knows about medical conditions and their treatment, as well as about community resources.

These activities will help you to develop an effective working relationship with your new service coordinator:

1. Make sure you know his/her name and telephone number, and find out when is the best time to call.
2. Arrange for a face-to-face visit so he/she can begin learning about you and your child. You might arrange for a meeting during your next clinic or doctor's visit to begin the team-building process.
3. Your new service coordinator has a copy of the Annual Service Plan that was developed by your previous service coordinator. Meet periodically and decide whether it still addresses your concerns. It helps to think about your current concerns ahead of time and write them down for reference during the meeting.
4. Keep your service coordinator informed of any changes, such as address, telephone number, medical condition, treatment plan, Medicaid or insurance status, or personal situation that might effect financial eligibility or services.

Over time, you should be able to work more and more effectively with your new medical home team. Through this process, you should increase your chances of receiving comprehensive coordinated care that meets the needs of you or your child.

Know your parental rights, school's responsibilities for special needs

taken from *The Business Review* - by Sandra Gordon

Children with special needs are entitled to a free appropriate public education, and have been since 1975, when Congress passed the Education of All Handicapped Children Act. Now called the Individuals with Disabilities Education Act, or IDEA, the law requires public schools to educate children with disabilities in the same classrooms and programs as children who are not disabled, to the maximum extent appropriate.

This requirement is known as education in the "least restrictive environment." Each state has its own laws to carry out IDEA responsibilities. In New York, we have the Title VI of the state Education Law. This article provides a brief overview of your rights and your school district's responsibilities.

As a parent of a child with special needs, your right to participate in your child's education is not only encouraged, it's guaranteed under state law. Your rights begin the moment you find that your child is having difficulties in school. If you find that your 3 to 5 year old preschooler is having difficulty, you can make a referral directly to your school district's Committee on Preschool Special Education (CPSE).

For your school-age child, you can begin by requesting regular education support programs like psychological services or speech and language improvement services. If those services aren't enough, you can refer your child to your school district's Committee on Special Education. The committee will help you decide

if your child has a disability that affects his or her learning.

Your participation rights don't stop when you make a referral to the committee. The committee includes you, and if appropriate, your child. Depending on your child's particular case, the committee also includes one of your child's regular education teachers, one of his or her special education teachers, a school psychologist, a school physician, a school administrator, a person qualified to interpret evaluation results, a person with special expertise regarding your child, and, unless you say otherwise, another parent of a child with a disability from the same or a neighboring district.

Your child's committee may have fewer members if one person can fulfill more than one role. For example, the school psychologist might also be able to interpret the evaluation results.

It is your school district's responsibility to set up the committee, evaluate your child's needs and abilities, and determine his or her eligibility to receive special education services—all with your input. The committee must have your written consent to evaluate your child. If your school-age child is found to be eligible, the committee will develop and implement an Individualized Education Program (IEP) within 60 school days of receiving your consent to evaluate. The committee will annually review and modify or revise the IEP within 60 school days of the annual review date.

For preschoolers, the committee will recommend appropriate services within 30 school days of your consent. Those services will begin on the July, September or January starting date of the approved programs, or within 30 school days from the date of the committee's recommendation.

The committee will reevaluate your child no less than every three years. In keeping with the least restrictive environment rule, the committee must consider regular education programs in combination with supplemental aids and services before any alternative placement. The committee will not remove students with

disabilities from the regular school program unless education in regular classes with supplemental aids and services is unsatisfactory. If the committee recommends placement in other than a regular classroom or program, it will justify that recommendation in writing.

The school district may even be required to reimburse you for placing your child in a private school. To be reimbursed, you would have to prove, at a hearing, that the school district didn't provide your child with a free appropriate public education, in a timely manner, before you enrolled your child in a private school that meets his or her needs.

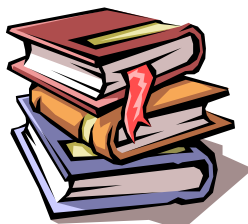
In addition to your right to participate in planning and implementing your child's special education program, the law guarantees you certain procedural or due process rights. You must have prior written notice, in your own language, of any action the committee plans to take. You must have notice of meetings telling you the purpose of the meeting, when and where it will be, and who will be there. All notices must list the procedural safeguards to protect your due process rights. Among them is the right to a hearing to settle disagreements about your child's education plan. You can appeal hearing decisions all the way to state level, and beyond that to the courts.

Remember, this is only a summary of your rights and the school's responsibilities. The school district will provide you with information on all of your rights in much greater detail. All you have to do is ask.



Books – the perfect disability awareness tool!

taken from MomPlanet – by Lisa Simmons



I don't know any parent or teacher of young children that doesn't believe in the benefits of reading to kids. Virtually all of them include "story time" in their daily routine. Books have the power to capture a child's imagination and take them on wonderful journeys. They also have the power to help them understand new things and to send positive messages. All of these qualities make books an ideal choice when adults are searching for ways to help non-disabled children to understand the world of a child with special needs. If you are a parent or a teacher interested in doing some simple disability awareness training, then I would offer these tips:

1. Start with the right story.

Select a story that your reading audience can relate to, but also select a special needs that will be relevant to their life. Do you currently have a special needs child in your class? Do they have friends or neighbors with a disability? Do you know someone who could come and talk to the class as a friend or guest about their own disability? Use your chosen story to help everyone relax. Young kids relate well to the characters in stories. If you use a story with a positive message it will help set a great "tone" for what you'll be saying later.

2. Don't stop with just the story.

After the story, be sure you take advantage of the "teachable moment".

Talk about the things that can be more difficult for a child with special needs. Young children are naturally empathetic. They feel the pain of the book character that gets hurt and worry about the fate of their favorite TV character when he's in trouble. Don't be melodramatic about things; just be "real" about what tasks would be harder for a child with the disability you are discussing.

3. Include a child or adult with special needs.

This can be accomplished by inviting an adult with disabilities to your classroom as a guest, including a current or former special needs student as the "star" of your discussion or as parents just taking the opportunity to introduce your child to individuals with disabilities that are friends or acquaintances. This step is important because it reminds the kids that this is real life, not JUST a story. If you are worried about making the discussion awkward, then schedule the visit for a day or two after your story. This will allow the visitor to have center stage and give the kids a couple of days to think about the story and your follow up discussion.

4. Tell them how they can help!

If you are doing the awareness training to support a current class member, then do some pre-planning with the other adult involved (the child's parent if you are a teacher or vice versa). Decide together what support roles classmates can play. Will there be a transition buddy to help the child find areas away from the regular classroom? Will anyone besides the teacher be pushing the child's wheelchair? Is it important for someone to sit next to them who can help them find activity supplies? Kids are natural helpers and this is a wonderful time to ask for volunteers who like to help out. Just remember to talk about exactly what they will need to do and when they should do it (i.e. only when the teacher reminds you, every day after recess, etc.). For a more general discussion, it may be enough just to talk about issues like not teasing, ways to offer help respectfully, and different ways to communicate with each other.

communicate with each other.

5. Remind them we're more alike than we are different.

This is a great opportunity to help everyone see that kids with special needs are really just kids. You've already addressed how he or she is different, now spend some time talking about how s/he's just like them. Help lay the groundwork for future friendships by talking about all the "regular kid" things your current class member or invited guest enjoys. Practice a simple conversation about their interests that you and the special needs child can have in front of the class. Not only does the child have the opportunity to share about themselves, but also you demonstrate how to communicate with him/her in a very non-threatening way.

6. Answer questions honestly and address fears.

This is probably the most important thing you can do. Allow as much time as this takes so that you've answered all questions to the best of your ability. It will probably help to think through some possible questions and answers ahead of time just so you can phrase your answers in kid-friendly words. If you're not sure what questions they may ask, think back to when you first heard the child's diagnosis. What questions did you have? Chances are the classmates will have similar fears. Can he play games with us? Will I hurt her? How do I ask her a question? Will he ever be able to ...? (talk, run, etc.)

Hopefully these tips will encourage you to include stories as a frequent awareness tool in your home or classroom. If you are interested but not sure what books to use, you can find some excellent choices here.

For kids age 4-8: <http://www.ideallives.com/generic.jhtml?pid=81>

For kids age 9-12: <http://www.ideallives.com/generic.jhtml?pid=125>

Save the date!

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Don't miss this opportunity to learn about new assistive technology devices and services, educational policy and practices, and the latest in information technology accessibility. Learn ways to enhance and promote the independence and quality of life of people with disabilities. Network with therapists, independent living specialists, consumers, teachers, AT Specialists, Rehabilitation professionals, IT and media specialists, and service providers.

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For more information visit www.dolir.state.mo.us/matp/ and click on "Conference & Training".



Chat with the chief

by Rick Horrell

The mission of the Bureau of Special Health Care Needs is "to develop, promote, and support community-based systems that enable the best possible health and highest level of func-

tioning for Missourians with special health care needs". At the Bureau, we are constantly striving to carry out this task to the best of our ability by focusing our activities around the six goals included in the President's New Freedom Initiative, Executive Order 13217 that was issued in June of 2001. These goals are:

1. Development of community-based systems of services that are inclusive of children with special health care needs (CSHCN) and their families, where substantial decision-making authority is devolved from the federal government to the states to the communities.
2. Recognition that families are the ultimate decision-makers for their children and encouragement of participation in making informed decisions.
3. Development of standardized elements of the medical home for CSHCNs. In addition, the agency will develop and disseminate models of the medical home, and provide additional training resources to primary care professionals to develop medical homes.
4. Review of the variety of reimbursement mechanisms that impact children with special health care needs.
5. Through the Maternal and Child Health Block grant (Title V of the Social Security Act), and the Newborn Genetics Program (Title XXVI of the Child Health Act), expansion and strengthening of newborn screening systems and promote ongoing screening of CSHCN (incorporating EPSDT into the medical home concept).
6. Ensuring that youth with special health care needs receive the services necessary to transition to all aspects of adulthood, including from pediatric to adult health care, from school to employment and to independence.

Staff have been working diligently on reorganizing our programs to better serve our participants and their individual needs. Consequently, the bureau has now been structured into four life-stage programs and three operational groups. Programs organized according to life span periods can better address the unique biological, cognitive, and social processes for

each period of development for individuals with special health needs. The life-stage programs include Infants and Toddlers (ages birth to 3), Children (ages 3-13), Adolescents (ages 13-21), and Adult Transition (ages 21-65). The three operational groups are the Internal Resource Group, the External Relations Group, and the Office Support Group. By making these changes to our approach in serving our participants, we believe that services can be more tailored to each individual group or life span. The Bureau looks forward to assisting you in the years to come.

If you have questions or need assistance, please feel free to contact us at 1-800-451-0669.



You Have Taught Me

by Anne Maclellan

You have taught me patience
to rejoice in small gains which others
take for granted.

You have taught me tolerance
to accept that your perspective is
different
and deserves respect.

You have taught me courage
to fight for you when no one else will.

You have taught me endurance
to go on when I feel I can't any more.

You have taught me humility
to accept when I can't make things better
but can only be here for you.

You have taught me to love
at a deeper level than I ever thought
possible.



Moving from pediatric....

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vider who may not be as familiar with the specific condition or need.

On the other hand, many individuals say that their pediatric providers have not addressed adult issues. They report feeling embarrassed and demeaned as young adults who are in their 20s or even 30s, and are still seen in pediatric offices, clinics, and hospitals. Pediatric-trained providers can sometimes miss signs and symptoms that would be recognized by adult-focused providers.

The transition to adult care would seem to be most effective and most easily achieved if it was anticipated and planned for from the earliest point in the child's treatment. So that youth and families do not feel forced to change providers or do not feel trepidation over the quality of care to be received in the future, the transition should be expected, well thought out, and managed to minimize any negative impact. It should be one more informed choice made by the patient, family, and health care provider. That is the course taken in the HRSA's National Healthy and Ready to Work (HRTW) initiative.

HRTW projects

The six state implementation grant projects (Arizona, Iowa, Kentucky,

Maine, Mississippi, and Wisconsin), currently running in Phase II of the HRTW initiative, are all looking at the issues involved with transition from pediatric to adult health care.

The Kentucky TEACH project has changed the way the Kentucky Commission for Children with Special Health Care Needs interacts with the children and families. Through the use of "Life Maps" and introduction of a computerized tracking system, the Kentucky commission now focuses on transition at every point of contact with the child and family.

The Life Maps are designed to both

population of children and youth.

This change in focus at the commission was achieved, in part, by changing the job descriptions and performance plans of staff to reflect transition as a required element. That signaled to the staff the importance and value of transition as part of the services provided by the commission to the citizens of Kentucky.

Using the medical home

In addition to the issues that youth, families and pediatric providers face, finding adult providers who are willing and able to accept youth with special health care



.....to adult medical care.

elicit information about the child's status and progress and to give age-appropriate advice for ways the family can help prepare the child for future transition. Information is put into a database, and it is then available for future contacts with the child and family. This gives the commission staff a focused way to track the child's progress, identify specific family needs, and match with, or refer to, available resources. It also provides management information data for this

needs into their care can be a challenge in certain parts of the country. A number of the HRTW projects are approaching this issue as a part of the medical home concept.

The thinking is that comprehensive and coordinated care in the medical home would include planning for a transition to an appropriate adult provider. The grant project in Arizona, for example, has recruited adult providers who work with the

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various health plans and are willing to accept youth with special health care needs as patients. Linking those providers with the medical home will hopefully ease the entire transition process. It is already clear that a training need exists and the HRTW initiative will be focusing on how to address that need with the adult provider community.

Also, the HRTW initiative and the state implementation grant projects are looking at ways to address the insurance issue. In general, lack of information is a major factor. It seems that many youth and families would benefit from the assistance of a transition coordinator or facilitator who would help them explore the various options and find access to needed care, services, and insurance.

Cultural issues

Furthermore, there are cultural competency issues that impact access to and utilization of health care. Some minority populations are historically underserved

For more information about the New Freedom Initiative, visit www.hhs.gov/newfreedom

For more information about the SSI program, visit www.ssa.gov

For more information on the HRTW initiative, go to www.mchbhrtw.org

as stated above. The situation worsens as these youth move into adulthood. Some cultures have different values about health and health care that may impact issues, such as if, or when, treatment is sought, whether or not medications or invasive procedures will be used, and at what age youth will begin to exercise control over medical decisions. When providers are culturally competent, care improves and families express increased satisfaction. The HRTW National Center is working with the National Center on Cultural Competency to further identify and address the needs of minority youth in transition.

By providing youth and families with

as much information as possible and building a system of care that encompasses the medical home concept, including planning for and facilitating the transition to adult health care, the HRTW initiative aims to enable youth and families in making choices that allow for a full, rewarding, and independent life in their community.

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